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Title:

"Healing, referring, supporting but not interfering": Traditional healers' experiences of HIV management in five South African communities taking part in the HPTN 071 (PopART) trial.

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Research Assignment

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Degree: MPhil in Transdisciplinary Health and Development Studies

Date: March 2020

Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Signature: N Vanqa

Date: March 2020

ACRONYMS

AIDS - Acquired Immune Deficiency Syndrome

ART - Antiretroviral Treatment

ARV - Antiretroviral

DoH - Department of Health

HIV - Human Immunodeficiency

HSRC - Human Science Research Council

MRC - Medical Research Council

PLHIV - People living with HIV

SA - South Africa

STI - Sexually Transmitted Infection

UNAIDS - United Nations Joint Programme on HIV/AIDS

WHO - World Health Organisation

Contents

CHAPTER 1: BACKGROUND AND OVERVIEW

This study forms part of the HPTN 071 (Pop ART), a three-arm cluster randomized controlled trial implemented in 21 peri-urban study communities in Zambia and South Africa between 2013 and 2018. For this sub study, data forms part of the socio-behavioural component from five South African communities of the trial. The trial aimed to explore strategies that might support the UNAIDS/WHO 90/90/90 targets aiming to have 90% of infected people knowing their HIV status, 90% of HIV-positive people initiated on ART, and 90% of people treated with ART and become virally supressed. Reaching these targeted goals requires understanding different forms of care used by people living in these communities, including traditional healing. Thus, the aim of this sub-study is to understand traditional healers' perspectives on their role in HIV management and care. To contextualise this, the project has also explored the history of traditional healing in South Africa and the current position of healers in a bio-medically dominated health system.

To achieve this aim, the study explored the different types of health providers in these communities other than biomedical care, understanding who these healers are, how they provide care and to whom they provide care in the communities where the trial was taking place. I further explored the inclusion of HIV care in their services and how they might have influenced its current state in the medical sector, with regards to how they might collaborate to support and achieve better outcomes in the fight against HIV.

There are disparities and inconsistencies in managing health care that affects people and their diverse health practices including traditional health in South Africa. In order to correct the past mistakes that affected health care, there needs to be processes of negotiation based on what people want and what works best for them and that requires input from both the society to the government. In response to correcting the past social ills caused by colonialism and to merge

different services, the post-apartheid government passed the traditional healer's act which has not yet been active. The Traditional Health Practitioners Act 22 of 2007, is aimed at providing a regulatory framework to ensure the efficacy, safety and quality of traditional health services, to manage and control over registration, training and conduct or practitioners and students (Street, 2016). According to Leclerc-Madlala (2016) and Zuma et al, (2018), the South African Department of Health (DoH) acknowledges the role played by traditional healers in providing a specialised mode of care and recommends that behavioural, cultural and medical interventions to HIV care to be combined.

1.1 **Introduction**

For many individuals living in South Africa, seeking health care involves negotiating between different healing systems (Wreford, 2005). These health systems can be simplistically divided into biomedicine and traditional healing, although the boundary between them is sometimes more fluid. The South African traditional care is used mainly because of its ability to divine the cause and source of a person's illness or social problem in a spiritual manner however, it is used concurrently with biomedical care (Zuma, 2018).

There are social and historical effects left by the apartheid that have had a negative impact in health to many South Africans with inequality of health services amongst others. Racial segregation resulted in disparities in the health and medical sector, creating an environment that placed some groups at a disadvantage while playing in favour for the other (Comaroff, 2007). Colonialism and the apartheid regime created those systems that controlled systems around health care, health and transformation and focused on a biomedical approach to care (Feierman, 1985; Deacon, 1996). Because of these system, laws and policies were passed to dismantle the formal recognition and operation of traditional healers, (Davenish, 2005).

While many South Africans are adapt at negotiating care within a plural healing system, there are important barriers to effective collaborations between biomedical service providers and traditional healers. Tensions between biomedical service providers and traditional healers in the contemporary health system are shaped by historical patterns emerging from colonial and apartheid policies and practices. These restrictive health policies, promoted biomedicine and biomedical care as superior than other types of care and acted as a barrier for the formalisation of the traditional healing profession (Kassaye et.al, 2006). Further, the current system of formal medical training and service delivery privileges the biomedical system. Despite these challenges, researchers have highlighted the necessity of developing more effective collaborations in order to ensure holistic care for the diverse people of South Africa (Moshabela et.al, 2016).

In the current times where HIV is one of the challenging illnesses in Africa, public health takes an approach to understand the construct and conceptualization of diseases with various approaches to care (Hahn, 2018). This means managing an illness is not only about providing a person with medication; there are social, psychological and spiritual elements that plays part in a person's well-being.

South Africa has approximately 7.9 million people living with HIV (PLHIV) (HSRC, 2018). In response to the epidemic in 2014, the UNAIDS/WHO proposed 90/90/90 treatment goals that 90% of all people living with HIV should know their HIV status, 90% of those diagnosed should be on antiretroviral treatment (ART) and 90% of those should be virologically suppressed by 2020. However, there has to be more to think about in reaching these targets other than just testing and providing people with medication. Following the UNAIDS 90/90/90 proposal, in 2015 the WHO released an update on ART guidelines recommending that all persons living with HIV be started on ART immediately (WHO, 2015). South Africa adopted and implemented the treatment for all guidelines in October 2016 (Hayes, 2019).

While the government's focus on HIV care is based on making sure that everyone who is living with HIV is on antiretroviral treatment, previous studies showed that seeking health care in South Africa includes moving between two parallel pathways of care, the biomedicine and African traditional healing (Wreford, 2005; Zuma, 2018).

Knowing one's HIV status is the first step and getting people to care is another milestone, but helping people to remain in care and adhere to treatment are also key elements of managing an illness. According to WHO, adherence to treatment is defined as the extent to which a patient's drug taking behaviour corresponds to the agreed-to, prescribed treatment from the healthcare provider (World Health Organisation, 2003). Adherence is influenced by structural factors such as poverty and living conditions, social networks and support, the complexity of treatment, physiological and psychological factors as well as health services related factors (World Health Organisation, 2003; DiStefano and Schmidt, 2016).

Collaborative and integrational approaches in health care is key, it brings a sense of ownership while promoting initiative and responsibility to one's health. The movement of knowledge from one sector to another is important, it creates platforms of awareness on its' significance and contribution before creating boundaries and restrictions that prohibits this healing method (Flint and Payne, 2012). Given these changes in the HIV treatment guidelines, this study aims to understand the current working relationship between traditional healers and the biomedical health practitioners. To also identify ideas from traditional healers on how they might contribute in achieving better outcomes of care in the fight against HIV. This study will highlight the identified shortfalls and possible benefits of traditional health in the context of HIV management and care. It will further offer possible recommendations to expand research and

how best programmes could be implemented to address issues on how to support the scale up of ART and helping to retain people in HIV care.

By conducting research with traditional healers on how services are rendered, the study aims to understand what traditional healers require to improve HIV related services compared to how care is structured in the biomedical sector to meet the needs of PLHIV in the South African communities. In order to broaden knowledge and understand better what people want in a democratic society there is a need to rigorously investigate what different health services are available for use in our communities, and how best can they operate together. The study outcomes could be used to inform policy makers and health programme implementers with the best suitable ways of supporting universal treatment. Data for this study were drawn only from South African participants residing in five of nine peri-urban communities that took part in the HPTN071 (PopART) trial. These five communities had more traditional healers who were practicing and interested to take part in the study when approached and no healers were interested to take part in the other four communities.

1.2 Aims and objectives

The data used for this project comes from a sub-study of the HPTN 071 (PopART) HIV prevention trial conducted in South Africa and Zambia between 2012 and 2017. The topic of this sub-study emerged from a process of systematic community observations where researchers noted a number of visible practicing traditional healers in the communities. This drew an interest of understanding their clientele and services provides in HIV burdened communities. The primary aim of the study is to understand the current work done by traditional healers in HIV care and healers' perspectives on the challenges and dynamics of providing traditional health where ART is available as a biomedical management approach in the Western Cape of South Africa. To assess the benefits and implications of providing traditional healing to people living with HIV in communities taking part in the HPTN 071

(PopART) trial in South Africa, at time where ART is scaled up and easily accessible to all individuals living with HIV.

In order to do so, the study has four objective:

1. To describe how healers understand the role they play in managing and treating HIV and AIDS in the context of HIV treatment scale-up
2. To explore how traditional healers and health seekers negotiate care in a plural healing system
3. To understand the healers' perspectives on the advantages and disadvantages of providing traditional health services to people living with HIV
4. To explore the possible benefits of a successful plural healing system in the context of scaled up HIV treatment

1.3 Significance of the research

As a professional nurse who previously provided health care services, I have witnessed how biomedical health staff engage with clients on matters concerning traditional health. The majority of medical professionals I have encountered are not open to the use of traditional medicine and actively discourage their patients from engaging with the traditional healing system. This is perhaps why most of the research participants I have spoken to report that they hide being traditional practitioners and would withhold information to biomedical health professionals. The power of trust and mutual understanding between health staff and patients could create a conducive environment when participants are given a chance to voice what they want it will help in building a trusting relationship between clients and health providers. A trusting relationship is important because it allows people to raise some of their challenges with

medical treatment as well as to highlight socio-cultural aspects of their lives which may interfere with treatment and health care provided to them.

In order to broaden knowledge and understand better what people want in a democratic society there is a need to rigorously investigate what different health services are available for use in our communities. The majority of previous studies done on traditional healers were mainly focused on how traditional healers could be absorbed and work under the biomedical sector as opposed to identifying traditional healing as a legitimate practice on its own and engage it in collaboration processes (Akol et.al, 2018; Kayombo et.al, 2007; Semenya and Potgieter, 2014; Appelbaum, et al., 2014; Zuma et.al, 2018). There is limited research on how traditional healers manage their clients living with HIV and their views HIV management approaches, challenges and experiences of providing care and how they might support the treatment uptake and continuity in their communities.

Conducting research with traditional healers on how services are rendered in the context of HIV care will help us understand better how services can be structured to assist people to negotiate care between two health systems for improved health outcomes. Furthermore, the study will assist in identifying challenges faced by people using these two different health services as well as challenges experienced by health providers to meet balance. Study outcomes could be used to inform policy makers and health programme implementers with the best suitable ways of supporting universal treatment.

Conducting this research as a sub study of the main HPTN071 trial has both ethical and practical value. Ethically it is important to have the voices of research participants heard as they are the ones at the ground level providing and accessing these health services. Community members are also expected to comply with policies and procedures based on the outcomes and recommendations of the study findings done in their communities. It is important to engage with people in order to get a better understanding of how participants navigate health services

and how health providers improvise to meet people's needs in these communities. Engaging participants for an extended period of time provides researchers with an opportunity to capture patterns and changes in their lives, which contributes in knowledge that could be used in a larger context picture as well as giving context in the analysis of the findings. It is also important that research trials are designed in a way that accommodates conditions in which people live in, to consider context for a better understanding of the potential populations targeted. With the great amount of research done on traditional healing, there is still a lack of systematic description, exploration and comparison of traditional experiences towards partnership and collaboration among the biomedical and traditional sectors in light of treatment for all. Understanding the how care is rendered by potential partners in care such as traditional healers will help in structuring changes in HIV care. Once the views have been captured and conceptualised, further research can be done into other aspects of acceptability and potential collaboration.

CHAPTER 2: LITERATURE REVIEW AND OVERVIEW

In this section, I first present a brief overview of the South African history of colonialism and the impact it had on traditional healing and on health of the South African people in general. I proceed by giving an overview on how traditional healing is currently viewed in the context of HIV and describing some of the challenges that have been identified in making medical pluralism is a term used to describe a more complex system in which people seek care from, from diverse sources influenced by cultural, faith and traditional practices amongst others used in South Africa and around the world. The background and the historical context and current literature presented serves as a guide and a manner in which I introduce the research problem. I have highlighted gaps in the existing literature informing the research problem.

2.1 History of colonialism and effects on traditional health

Exploring the history of health interventions and healing systems in South Africa is important because it helps us to understand how the past shapes the present health systems and how they are viewed by the society and the world at large. South Africa is slowly recovering from colonialism, with historically informed power dynamics and disparities deeply affecting the lives of most black South Africans, including their healing and health seeking practices (Feierman, 1985; Deacon, 1996). Racial segregation policies and stereotyped assumptions on the racial dynamics of disease resulted in the introduction of standardised, controlled and unequal health and healing practices, which reinforced broader inequalities and power dynamics (Deacon, 1996; Coovadia, et al., 2009). In introducing biomedical care as the main source of care, the colonial and apartheid governments largely overlooked existing local healing

systems and practices, often associating traditional medicine and practices with witchcraft (Niehaus, 2010).

The biomedical health system is formulated and operates under policies and some of these systems might work differently when compared to traditional healing practices in terms of how the systems are managed and regulated. There were repressive legislations that were passed to control and suppress traditional healers, in particular the Witchcraft Suppression Act 3 of 1957 and the Amended Act 50 of 1970. The Act 3 of 1957 made it an offence for 'any person to exercise supernatural powers,' prohibiting rights of traditional healers to operate (Davenish, 2005). The restrictive health policies and the recognition of only western biomedical health and medicinal approaches to care acted as a barrier for the formalisation of traditional healing in South Africa (Kassaye et.al, 2006). These laws and acts further became a barrier to business for traditional health practitioners, preventing them from establishing formal practices and affecting their economic state as compared to their counterparts (Flint, 2001). In response to this injustice and structural disparities, the post-apartheid government initiated movements by formulating laws and policies to recognise and formalise traditional healers with the aim to unite and expand health services (Batisai, 2016).

2.2 Medical pluralism and coexistence of care in SA and Africa

Finding a common ground between biomedical and traditional healing systems is more difficult because of the South African history of colonisation, oppression and repression of traditional healing. Nonetheless, many South Africans access care from multiple healing systems, including biomedical care and traditional healing in what some scholars have defined as a pluralistic healing system (Thornton, 2015). Medical pluralism is defined as "the employment of more than one medical system or the use of both conventional and complementary alternative medicine (CAM) for health and illness" (Wade et.al, 2010). For most South Africans, traditional

healing and the use of herbal medication is an important aspect of their lives. The impact and contribution of traditional health requires consideration and has an impact from an individual, societal and national level in care, with possible better health outcome that requires consideration in managing different health problems (Feierman, 1985; Flint, 2015).

Research done on traditional health in South African communities suggests different views on this practice in South Africa, highlighting both positive and negative aspects of the practice (Zuma et al, 2016). These views are a result of queries and discussions held by health professionals and researchers in different platforms of research. These includes the questions on the legitimacy of the practice or practitioners, the need for registration of healers for control and training, as well as the safety of natural herbs used by traditional healers (Batisai, 2016). The questions of credibility and lack of trust in traditional healing is drawn on the comparison made based on the structure of biomedical care however, there is not much consideration on the positive difference and the uniqueness brought by each of these practices.

There is a great amount of work done around the globe in understanding the importance of medical pluralism for different aspects of care and diverse diseases, highlighting similarities and differences between healing practices (Meurk et al., 2012; Moshabela et al., 2017). Over thirty years ago a study was done by Edwards, (1986) in KwaZulu-Natal, South Africa examined the difference between traditional and biomedical healing systems post an experimental study done healing practices of Zulu healers and modern clinical psychologists for psychiatric patients. In the study, these different health providers were given an opportunity to interview psychiatric patients while the interview was being recorded. The aim of the study was to compare interviewing, assessment skill and treatment planning strategies used by traditional and biomedical healers. The researchers found that the distinction between modern and traditional medicine was based on the understanding and classification of the illness cause

and symptoms to either natural vs supernatural. Furthermore, findings from interviews done with traditional healers and psychologists showed that both practices were equally helpful to the patients and practitioners' in terms of identifying a diagnosis and treatment recommendations based on that diagnosis.

For any form of method of health care to be effective, policies must be in place to guide and create a standardized and accepted structure of operations. Policymakers can serve as the drivers of, or barriers to, collaboration if the policies have unreasonable standards such an approved qualification versus traditional and spiritual training. According to Flint and Payne (2013), policymakers often struggle with how best to engage with the supernatural aspects of care that form the basis of the traditional sector's approach. The success or failure of collaboration between traditional healers and biomedical practitioners using different systems is dependent on the ability of the policymakers and practitioners who control the formal healthcare system (dominated by biomedical health care) to allow space for a multi-dimensional approach to care.

According to Packard and Epstein (1991), principles of care and treatment that govern the study of medical conditions are assumed to be relevant to all issues of health, aiming at understanding the epidemiology of diseases amongst other factors. However, clinical research studies are mainly based on western knowledge and theories. In their 1991 study, these authors further argued that findings and recommendations for treatment were often made without adequate epidemiological data on the African context and were executed with limited knowledge about the societies and cultures within which these diseases occur. Similarly, over 20 years ago, Marks and Anderson (1987) argued that there was a lack of studies and inadequate data that would support claims and comparisons between traditional health and biomedical benefits made with other countries. The authors argued that the economic power influencing disease patterns made it difficult for comparison and interpretation of health disparities in the South African context. Furthermore, health patterns were based on larger social changes, rather than simply

on healing practices. Twenty years later, there is no difference to the current diseases and the association to political economy.

Lack of knowledge of traditional practices can also serve as a barrier to more collaborative approaches to care. A study done by Chipfakacha in Botswana in 1997 on traditional healers' knowledge of STIs and HIV found that there is work needed to be done to sensitise and support HIV education programmes that would provide information on the epidemiology and prevention programmes. The study found that negative assumptions about traditional healers were perpetuated by stories suggesting that other cultural practices such as scarification (the therapeutic use of razors used by traditional healers) can cause harm by spreading HIV (Chipfakacha, 1997). There has always been constant change in how health matters are addressed around the globe and the changes are recommendations are from studies done in local communities. In a democratic country like South Africa, with a choice and a right to care, it is expected that there should be systems that will accommodate its' people but up until now there are still unresolved issues with the traditional health sector.

2.3 Research on Traditional health and HIV

The HIV epidemic came at a tender time in South Africa, while the country was slowly recovering from apartheid and government taking actions in dealing with disparities at a national level (Didier, 2007). The effects of HIV in the country resulted in government health officials having to divert focus from other health challenges such as non-communicable diseases to this health crisis. In the mid 2000's, South Africa slowly acquired knowledge in response to HIV/AIDS leaning from research done around the globe, the biomedical antiretroviral treatment (ART) approach was proven to be the best choice of care to manage the epidemic (Campbell-Hall et al., 2010).

The traditional approach to HIV care of using natural herbs suggested by the late former minister of health Manto Shabalala-Msimang and former president Thabo Mbeki was

considered as part of the broader understanding as AIDS denialism (Baterman, 2006; Didier 2007). The *"Ubhejane"* concoction saga was one of the stories that had an impact on plural heath in South Africa. According to Beterman (2006) the late Minister of Health Manto Shabalala-Msimang was part of the research and claims made on "*Ubhejane,"* where some people in the Kwa-Zulu Natal area claimed to cure HIV through natural herbs. These claims were later proven incorrect but 'ubhejane' was determine to be a non-toxic concoction that enhanced appetite and improved patients' well-being. The falsified information has affected the credibility of the traditional healing system, and perhaps diminished the real value of some traditional medicines. Hence the lack of exploring the use and impact of traditional medication to HIV.

In any field of research, there needs to be rigorous investigation on the subject before conclusions are made. The same approach is necessary in understanding what traditional medicine can do for HIV management. Questions and investigation on subjects that are affecting people's lives are important on any category of care including both traditional and biomedical care. However, there will be challenges when two different systems are compared and in the case of traditional healing the comparison is often based on assumptions that emerge from the biomedical system (Nxumalo et al., 2011).

During Thabo Mbeki denialism period between 1999 and 2006, there was a noticeable rise of interest in South Africa in understanding various aspects of traditional healing and what it may offer at a large scale (Didier, 2007). During this period the controversy on the approaches to care recommended by the Department of Health under the former minister of health also triggered an interest to researchers in Africa in the role played by traditional healers in HIV treatment. Following the interest and shift to explore the use of herbs in HIV care, a number of research studies were interested in examining the safety of herbs used and assessing traditional healer's knowledge of diseases in comparison with biomedical forms of knowledge (e.g., Karim et al., 2009; Belisle et al., 2015).

When trying to understand healing in a broader and contextual manner, a study was done in six Eastern and Southern African countries on medical pluralism in the context of HIV (Moshabela et al, 2017). In the study, 258 PLHIV were interviewed, as well as 48 families who have lost relatives to HIV and 53 health workers who provided HIV services. The study highlighted that accessing multiple sources of care delays access to ART and creates interruptions in care, causing mistrust between service providers (Moshabela et al., 2017). There were also concerns raised about possible drug interactions with concurrent use of traditional, faith-based and western biomedicine by HIV positive people. The authors note, however, that this concern should not be limited to traditional medicine as drug interactions are possible with any use of a combination of drugs.

Another key element of research on traditional healing entailed exploring the possibilities of collaboration between traditional healers and the biomedical sector around the country. Studies were conducted in the major cities and the rural parts of South Africa as a way to understand the rationale behind a choice of a service provider (McFarlane, 2015). Results from a study conducted in KwaZulu-Natal as part of the Treatment as Prevention (TasP) at the African Health Research Institute formally known as the African Centre for Population Health, north of Kwa-Zulu Natal. The trial was conducted with a group of traditional healers providing services and community leaders highlighted the complexity of illness and stigma attached to HIV as one of the reasons people chose to seek care from traditional healers (Zuma et.al, 2018). The study found that some participants reported choosing to use traditional healers because of a fear of being seen at the clinic and thus being identified as HIV positive (Zuma et.al, 2018).

In the context of HIV, studies have also demonstrated that traditional health-seeking behaviour is influenced by gender differences, where more men opted for traditional care than women and men testing less for HIV (Treves-Kagan et al., 2017). Studies have also explored how other sociocultural, economic and political dynamics shape health-seeking practices (Batisai, 2016;

Zuma, et.al, 2018). These factors include practical concerns such as proximity of traditional versus biomedical health services, level of education, relative costs of services and transport costs to health facilities (Batisai, 2016).

Some studies have explored the complexity of healing systems in South Africa, looking beyond a simple binary between traditional and biomedical care. A 2015 study by Flint compared different African traditional healing practices with Native American practices in three South African provinces (Eastern Cape, Western Cape and Gauteng). The study, which also included traditional healers from neighboring African countries such as Tanzania, Angola and Zimbabwe, aimed to look at how biomedical and traditional health sectors could accommodate one another and explored the possibility and desirability of collaboration between healing systems. It further suggested engaging policymakers to find the possible best ways to facilitate that process. However, findings from this study, similar to other findings, revolved around the issue of traditional medicine proving a "complementary" contribution, rather than being recognized as an independent partner in care.

Findings showed that there were tensions between the researchers and some of the healers where some healers cited apartheid as a reason for them not being part of the formal health system, claiming that their healing practices are the original health methods for South Africans. They thus argued that people need to critically interrogate "which practice was here first and what compliments what."

When looking at the social aspects of HIV/AIDS, one cannot ignore issues of treatment choice and health seeking behaviors. It might sound like an easy and simple question to ask someone where they seek medical health, which could be easily taken for granted. However, social science approaches highlight how health-seeking behavior is intricately linked to time and context, making the process of accessing care a complex issue (Batisai, 2016). Other countries have been successful in practicing traditional medicine and incorporated it formally to their

health systems, South Africa as a democratic country should create safe spaces for its' people to benefit in the freedom of choice to care. There is room to learn from others as it has been the case in medicine and treatment research and development but consider our context and diversity for better health outcomes.

CHAPTER 3: METHODS AND OVERVIEW

3.1 Study design

The study draws on data collected as part of the socio-behavioral component of the HPTN 071 (PopART) trial. The HPTN 071 (Pop ART) is a three-arm cluster randomized controlled trial where the effects of an HIV prevention package on community HIV incidence were evaluated. The socio-behavioral component within the broader study aimed to contextualize and understand how families experienced the roll out of Universal test and treat (UTT) including immediate HI treatment. The longitudinal qualitative study conducted over a period of 18 months involving different kinds of people such as PLHIV, sex workers, men who have sex with men, facility-based health providers, as well as traditional healers. The aim of this qualitative cohort sub-study was to contextualise the experiences of people living with HIV (PLWH) and other people living in the communities taking part in the (PopART) trial (Hoddinott et al., 2018).

This study component used qualitative research methods. According to Christensen (2011) qualitative research design is an interpretive, multi-method approach that investigates people in their natural environment. Using a qualitative method is one of the best methods for the context of this longitudinal study because it allowed me to be able to learn and understand the participants at their own space through social interactions over time and linked to social structures (Burck, 2005). The method further allows me to explore ideas and concepts, probe and provides a window into the participant's thinking and allow probing with a quick turnaround for clarity and examples (Christensen, 2011).

This type of research is designed to offer rich, in-depth accounts that are descriptive of the phenomena that are being studied in a particular setting (Smith, 2007). Traditional healing is one of the unique practices that has been there for generations, the sample contains young and older healers who might have differences on approach to care while using the same healing methods. Times have changed and new diseases developed over time therefore, it is significant to use a method with qualitative principles to zoom into context and time as issues evolve (Tracy, 2010). This qualitative research design has the potential to incorporate phenomenology as a strategy of inquiry (Creswell, 2014). For this sub-study, the analysis draws on data collected with participants in the cohort who self-identified as traditional healers – either Igqirha (diviner) or Ixhwele (herbalist) and who lived in one of the nine South African study communities.

3.2 Study context

The HPTN 071 (Pop ART) study, and the socio-behavioural research conducted within it, was implemented between 2013 and 2018 in 21 peri-urban study communities – 12 in Zambia and 9 in South Africa (Hayes et al., 2014). The study communities were randomly assigned to different 21 clusters with three arms, selected from high HIV burden and low resource areas in the Western Cape of South Africa and across the country of Zambia. These study communities were defined as the catchment areas of government clinics, with approximately 55 000 people in each cluster and a total of 600 000 adults in all communities (Hayes et al., 2014).

The South African qualitative cohort included about 150 households living in 9 study communities in the Western Cape. The South African communities are peri-urban with populations varied between middle and low class areas with predominantly a coloured and black population. People who live in these communities come from different parts of the country including foreign nationals.

For the purposes of this study, data will be draw only from five out of nine study communities that took part in the (PopART) trial. We were only able to identify and successfully recruit traditional healers from these five sites. There were no traditional healers who were successfully recruited for participation in the other four communities.

Participants are from two districts the Wine lands and the Cape metropole. The Wine lands area is predominantly dominated by coloured population and the Cape metropole by black population. Racial distribution in the Western Cape is estimated to 42.4% coloured and 38.6% of black with the majority of black people coming from the Eastern Cape Province (Stats SA, 2019) The source of employment ranges between formal work, farm work, informal and construction based work with a an expanded unemployment rate of 22.7% of its 6,844,272 (Stats SA, 2019).

3.3 Study participants and eligibility and recruitment

As part of the qualitative cohort sub-study nested within the HPTN 071 (Pop ART) trial, nine participants' were interviewed who self-identified as traditional healers. The interviews were not limited to the person who is a healer or a PLHIV, but also included other 17 family members and close social networks to broaden our understandings of their social realities.

A systematic process of recruitment was done after the community observations took place, aimed at identifying and to select a wide variety of participants covering age and gender. Eligibility criteria included living in the study community and providing services as a traditional healer in and outside the community as well as accessing health services in the catchment area.

Snowball sampling design was used to identify traditional healers operating in study communities. Snowball sampling is a convenience sampling method, which involves having a few originally contacted participants relevant to the study initiate a sequence of potential participants, followed by linkages among a chain of potential participants based on a

prevailing social network (Griffith, Morris, and Thakar, 2016). In each of the five communities, after one healer was recruited, researchers asked for referrals to other healers who were potential participants. In one of the communities the chairperson of the Western Cape Traditional Healers Association who was a participant invited the researchers to one of the general meetings to come and present the study and possibly recruit more participants who were purposively sampled to represent a wide variety of community views.

The demographics of participants who took part are shown on the table below.

Table 1: Interactions with participants and demographics

Site	Family number	No of recorded Interviews	Visits with no recording	Demographic Age	Demographic Sex	Demographic Race	Type of a healer
S19	Family No 1	12	1	57	Male	Black	Igqirha (diviner)
S14	Family No 2	10	2	51	Female	Black	Igqirha (diviner)
S14	Family No 3	7	2	48	Female	Black	Igqirha (diviner)
S14	Family No 4	1	0	31	Female	Black	Igqirha (diviner)
S15	Family No 5	9	0	59	Male	Black	Ixhwele (herbalist)
S14	Family No 6	2	2	56	Male	Black	Igqirha (diviner)
S16	Family No 7	10	0	27	Female	Black	Igqirha (diviner)

S15	Family No 8	2	0	61	Male	Black	Igqirha (diviner)
S15	Family No 9	2	0	65	Male	Black	Ixhwele (herbalist)
	Total	**55**	**7**	59	Male	Black	Ixhwele (herbalist)

3.4 Data collection processes

Data for the qualitative cohort study were collected by a team of researchers through a mix of social science research approaches between March 2016 and September 2017. Ethnographic and participatory research principles were used. All discussions were recorded using voice recorders. Photos were also often taken, and researchers wrote field notes and post-interview reflection documents to capture their insights. All interactions took place at participants' homes within the study communities, with visits scheduled at two to six week intervals over a period of 18 months.

Data collection was structured into different themes implemented sequentially but with flexibility to iterate between topics: (1) household, kin, and relational networks, (2) place and space, (3) getting by, (4) sex, love, and romance, (5) HIV service access, and (6) horizons, ambitions, and fears. Interviews and discussions were facilitated by graduate-level researchers and a research assistant in the participants' preferred language.

These participants were each visited between eight and twelve times over the course of eighteen months.

A total of 62 interactions (interviews/discussions) were conducted with the nine healers and their families included in this sub-study, amounting to a total to 55 recorded interviews as tabulated below. I conducted 25 of the total interviews and the remaining 30 was divided

between four pairs of researchers. Reflection documents and hand-written notes were also documented during the activities.

3.5 Data Analysis

The first step of the data analysis for this project included reading of all transcripts, field notes, activities documents and reflection documents for each of the nine healer participants and their families to select relevant data to be used. This process was followed by selecting themes discussed (their views on their role, the types of services they provide and how they think they could be included in the future of HIV care). Transcripts were read while listening to the recording in order to capture any missing details or nuances.

Thematic memos were written addressing key themes of discussions and select key quotes were captured in a spreadsheet. Following this initial review of the data, narratives were generated and grouped by similarities and differences that link to the key study questions. Narrative analysis focuses on how individuals present their accounts views of personal experiences to make sense of those lived experience, both constructions and claims of identity (Burck, 2005). Descriptive narratives linked to the themes were written in English, with tabulated quotes based on participant's experience of providing care and accessing care, their central roles and services provided, the dynamics between accessing care between traditional healers and the biomedical sector, and suggestions for how traditional healers can contribute in the scale up of HIV treatment.

This method and its processes was best suited for this study because it allowed me to get to understand the traditional healing practice by comparing descriptions, views and treatment methods used by each healer under each theme. This allowed me to identify similarities, differences and ways in which they improvise when providing HIV services based on their knowledge, training and experience.

3.6 Ethical consideration and participation

The HPTN 071 trial, including the socio-behavioral science component nested within the trial, was approved by the London School of Hygiene and Tropical Medicine, University of Zambia and Stellenbosch University research ethics committees. Enrolment and participation in the HPTN 071 Pop ART study was done voluntarily. All participants signed written informed consent per guidance of the in-country research ethics committee. As part of the consent process there was section that asked participants to give consent or opt out if they do not wish for their information/data to be used for a secondary study.Household participation was by consensus of all household members. Participants were allowed and able to withdraw from the HPTN 071 Pop ART study at any time and this was explained at all visits. It was explained that if the participant decided to withdraw data previously collected would still be used. For this study, data from both participants who were consented but dropped out and those who completed the study will be used.

Strict measures were taken and are still in place to safeguard confidentiality of data. Personal identifiers on paper are stored in a locked cabinet. Electronic data with personal identifiers are stored in separate dataset with password protection only accessible for designated staff (for computers and servers). Hand-held devices are password protected and personal identifiers are stored in an encrypted format. Confidentiality will continue to be maintained by not revealing participant's identity, images or recordings and follow the standard operating procedures of data storage to ensure and maintain confidentiality.

Participants did not receive any cash incentive. However, in South Africa research staff had discretionary allowances of approximately R80 (6 USD).

All data are stored securely and reported on using pseudonyms to protect participant confidentiality. Personal identifiers were removed from transcripts prior to analysis.

3.7 Risks and benefits

This study poses minimal to no risk as the data is drawn from existing data. Participants were not exposed to any direct medical risks for participating in the socio-behavioural component of the HPTN 071 Pop ART study. The "minimal risk" of participation was similar to that which a person might experience in their everyday lives. At a family or individual level, participants might have felt disempowered by having an HIV research agenda imposed on them or they may have been placed at risk of stigmatization by community members through ongoing contact with the research team. Participants also ran a risk of indirectly disclosing their HIV status to their family or others through the discussion sessions. There were no direct benefits to research participants but the research provided an opportunity for participants to open up and talk about some life challenges they are faced with. Because this data has already been collected, there are no additional risk involved in the analysis.

3.8 Context of the researcher

In qualitative research, the researcher themselves shapes the kinds of data collected in important way. In this section, I critically interrogate how my own background and positionality shapes the project.

As a professional nurse, my previous work was mainly focused on providing clinical care to patients and shifted to research working in a multidisciplinary team as a socio-behavioural science researcher. After qualifying as a professional nurse I worked at a hospital level. I noticed that at a point of being treated at a tertiary institution, a lot of patients had already progressed and reached complicated stages of illness. Most of what resulted in people being hospitalised appeared to be around lack of knowledge and missed information at a primary care level. I thus decided to move to a primary care facility, with an interest in providing services to mainly young people around HIV and reproductive health issues. I found that the extensive

work done by health professionals at both primary and tertiary institutions did not seem to be making much differences on HIV incidence and prevalence.

At the time, I had had very little opportunity to consider the impact of social context on health. I was, however, trained to look at patients in a holistic manner. In the clinic, I saw new people daily, but also spent years treating others, getting to know them slowly over time. Through these encounters, I developed an interest in working at the ground level in research, to be close to people and get to understand them at a personal level. I presented myself as a researcher to the participants, explaining in detail what my duties were and did not disclose my nursing background because my past work experiences were not part of my current work. However, with all participants during the conversations I disclosed that I am a nurse by profession deliberately with holding that information to avoid making them uncomfortable to express their views and experiences bout health services and interaction with biomedical staff. However, during the course of interaction after we had built a relationship they learned that I was a nurse by profession and I explained that it should not affect or influence how they interact with me and the rest of the team.

Through qualitative research, I hope to gain insights into how and why people make health decisions and explore family and social dynamics shaping care. I have always strived to do work of the highest ethical standard and feel that people's voices matter. Working on the HPTN 071 project afforded me the opportunity to pursue this research interest. Doing this research has given me a better understanding on some of the choices people make and how should people be accommodated as individuals in health care services.

CHAPTER 4: FINDINGS

Results presented below summarise traditional healers' views and experiences on the role they play in managing their clients with HIV, highlighting some challenges they are faced with working in a system dominated by biomedical care. Then, I present findings on how healers think their skills could be utilised in scaling up HIV services in order to reach different groups of people through using specific social support strategies and networks, helping more people to know their HIV status, and highlighting systems-related tensions, barriers to HIV care and treatment as well as treatment adherence.

4.1 The roles that traditional healers' see for themselves in expanding HIV services

4.1.1 Services provided by healers to HIV positive clients

Four themes were identified as common strategies recommended by traditional healers for their probable contribution to expanding HIV services. These included using herbs to boost immunity; emotional and psychosocial support; HIV testing/referral and treatment support/adherence. The recommendations were similar in both traditional healer categories (diviner and herbalist) even though their healing techniques differ in some aspects. All respondents indicated clearly their inability to cure HIV and AIDS.

> *"HIV requires treatment from the clinic, I always tell my clients to drink their ARVs and I am very careful to give them herbs if they are weak because herbs can help you to get better and be strong but can also be dangerous if you are too week" (Female healer, S14).*

Even though on interactions with traditional healers they reported to be providing particular care to PLHIV amongst other services, when directly asked about these HIV services none of

them had specific treatment made for HIV clients. All healers confirmed they are unable to cure nor treat HIV specifically, stating that no healer using herbs can cure it. Herbs that they use are meant to strengthen the immune system and treat other symptoms related to loss of appetite and weakness are considered as the best treatment for PLHIV as it is for any client.

> *"No you can't cure HIV, that thing is in the blood in your whole body and those who say they can treat it they are lying"* (*Male diviner, SA19).*

> *"Any healer who claims that they can cure HIV is a liar, HIV is a very complicated illness but there are people who come here very weak and fell strong and better after drinking a bottle or two of my herbs" (Male herbalist, S15).*

> *"Lady if you say you can cure HIV you are a liar. I have been in this business for a long time and we heard there were diviners who claimed to cure it but it's just a lie and you see, I have family members who have HIV, if there was a cure I would have helped them"(Male diviner, SA15).*

Traditional healers also explained their role as looking after a person's wellbeing holistically by focusing not just on individuals, but rather on families. Some problems are defined as too complex to handle in a medical manner excluding all other aspects of a human being, they understand that they require family as involvements as a whole rather than just focusing on an individual.

> *"Sometimes people come here alone and very sick, I would note that they need medical help but there would be things that requires family interventions for a person to be better like some rituals. That is when I try to ask them to bring their family members into the process so that these could be done properly" (Male diviner, S19).*

> *"At times people are sick and they know that they have HIV but they are scared to tell their partners or families and they use us to break the news in a way just like I was scared to tell my partner (Female diviner, S16).*

It appears that healers understand HIV to a particular degree, in that they know what types of benefits their treatment can offer to people. The majority of ways highlighted in the scaled up care is mostly based on linkage to care, testing and referral as well as psychosocial support that medical treatment. Ways of supporting HIV testing and treatment scale up is further explored on recommendations by traditional healers.

4.1.2 Negotiating care in a plural system (Included but not part of the system)

There is no formal relationship structure between traditional healers and biomedical care providers working in these communities. Despite this, healers continue to do what they claim to do best which is providing care to the people. When participants were asked about their relationship with health facilities and biomedical health service providers, they expressed that their engagement is infrequent and usually occurs only when it is perceived to be beneficial to the biomedical sector's goals. Healers described the conditions in which they are included as opportunistic and one sided agenda driven. One male herbalist, for example, recounted that he had recently been trained and educated on tuberculosis (TB), which has been identified as a major health challenge in the Western Cape.

> *"They involve us for certain things like the training we went to recently on TB symptoms, they tell us to ask and look out for these symptoms [pause] so that we can identify and refer clients to the clinic for them" (Male herbalist, SA15).*

Interestingly, in describing his involvement with the biomedical system another healer expressed his happiness in being part of the workshops.

> *"These workshops are also helpful to us, just like the rape workshop we had. They taught us how to deal with a rape case, if someone can come to us saying their child has been raped, so that we can know what to do or where to send them, as well as how we can also protect ourselves from being accused of these things and how to handle our clients" (Male herbalist, SA15).*

Because of the perceived negative impact of healers to HIV and experienced stigmatisation, one healer explained that the majority of their clients have to hide use of herbal treatment to the biomedical health facility staff and this is a concern to healers.

> *"Those nurses and doctors don't want to hear anything about traditional medicine, you haven't heard how bad they talk about us, what is funny is that some of them come to us at night when no one can see them" (Male healer, S19).*

Most healers shared a concern that in the absence of a formal and active relationship between them and medical professionals as the main barrier and a threat to treatment scale up, particularly affecting their role in HIV management e.g. the pathways of referral and treatment. They expressed loss of hope for genuine collaboration, despite all the meetings they have been engaging in with the Department of Health officials. Healers described feeling like there is indirect engagement with them by the health sector, usually carried out through non-governmental organisations (NGOs) operating in communities.

> *"There hasn't been any collaboration or a working together strategy between us and the hospitals or clinics. And the hospitals haven't made a clear plan. They only talk to us when we they want us to help" (Male diviner, SA14).*

Towards the end of discussions with healers, some of them felt like they deserved to receive some sort of recognition in participating in research towards a common goal in a fight against HIV. They supported this by requesting certificates that will demonstrate their contribution.

> *"At the end of this study what can we get? You must give us certificates that we show to people and our clients that we were part of HIV research and we are making a difference in the communities" (Male diviner, S19).*

The impression given by this request appeared as a way of striving to be recognised in the general sector of formal medical care, as well a way of having certification as it done in the biomedical sector.

The answers received from healers did not reveal any positive interrelationship between them and biomedical care practitioners, they mostly expressed their grievances and dissatisfaction. Healers expressed a general feeling of being used by the biomedical sector that caters for their needs and benefits. They also stated that there is still a long road to be travelled before the traditional and biomedical health systems to reach a point of consensus in working together. On the other hand, healers consider the education and training programmes they have received to be valuable and beneficial to them and the society. In addition, healers reported that they use the knowledge for both themselves and their clients' protective measures while they are also able to promote wellness and awareness.

4.1.3 A threat to the health system (Tensions with biomedical system but finding their way)

Traditional healers indicated that their services are not limited to communities where they live but expands beyond their surroundings, as people come from various places. Some expressed that they feel unrecognised and not considers by the biomedical sector as valuable through exclusion and discrimination that they have experienced.

> *"You know what my girl, I have struggled to get help many times when I went to the clinic. I took one of my clients there to get emergency help because he was in a critical*

condition, those nurses just looked at me and ignored me when I explained that I am a healer and the situation I was faced with" (Male herbalist, SA 15).

Healers expressed that there is a general assumption from some public members and biomedical care providers that they interfere with HIV treatment due to lack of HIV formal education, training and knowledge. These are assumptions are made based on comparison between them and biomedical professional and because the majority of healers are not well educated when compared to nurses and doctors. Overall, healers felt like there is a negative stigma imposed towards traditional healing and medicine. This not only affects their collaborative actions with the biomedical sector, they explained, but also affects how they are received and treated at a personal level when accessing care in health facilities

The participants noted an understanding that they have a potential advantage in terms of providing and support for effective care because they know the living conditions of their clients, what is available to people and the quality of services available in the communities. Their experience extends to understanding social challenges experienced by people in these communities and frustrations about clinic based medical care. Healers expressed using various strategies to accommodate their clients which they claim it could be beneficial in scaling up HIV care. They claim that they ensure their needs were met, including addressing issues of affordability, reducing time travelled by clients and allowing more flexibility for consultations hours as compared to standardised health care. Their view is that these elements of their offering could be an advantage to ART services as well.

"There are times where I see that this person knows his HIV status but is in denial and does not accept what is wrong with them and hopes that I will tell them something different. That is where I try to probe about other treatments they take and medication intervals to rule out use of ART. And if I find out that they have stopped treatment I

encourage them to restart. One of them was scared to go back to the clinic because the nurses would shout at him. I had to accompany him and give support and help him get back on treatment" (Male diviner, SA19).

Overall, I found that participants' narratives around why they feel they are excluded and considered a barrier in HIV management, as well as on other health conditions, are influenced by a number of factors. These factors include: assumptions that they have poor or no knowledge and understanding of the epidemiology of diseases, concerns around the safety of the herbs used and worries about drug interactions. However, they believe they have expertise that the nurses and doctors don't have which could complement biomedical care with better health outcomes.

"We want to help, if we can also be accommodated at the clinics or hospitals by having our own space and be consulted when there are issue that needs our expertise that would be great" (Male diviner, SA14).

Healers also highlighted that the experienced or perceived scepticism from the biomedical health workers is due to lack of understanding of the spiritual component of the traditional healing practice and that works as a disadvantage for them to be taken seriously. Participants' sense of being a "threat" is based on the assumed potential of hindering people to use biomedical treatment effectively or concurrently with herbs as well as the potential negative influence on ART such as treatment interruption even though the do the opposite of what is thought of them. In the example below, the healer uses an analogy to give clear and simplified explanations to his clients who are on treatment to ensure better understanding.

"I encourage people to take their ARVs because they work. They work because when a person uses treatment correctly the virus gets drunk, mos. It doesn't make it go away but it makes it drunk. You see, since they are made for you to take them at eight, if you

> *take them at eight you will take them again at eight. They are made to work in your blood for that 24hrs period. That thing, the virus, will remain drunk, yeah, and then when the pill gets weak in your body it will be time for you to take another one" (Male diviner, SA19).*

Healers claimed that the anticipated treatment interruptions could possibly happen when a client takes herbal treatment while on other chronic treatment and a person might decide to stop their ARV during the course of herbal treatment and resume after. Healers felt that these concerns were largely unfounded, and described how they often actively support biomedical treatment, which they saw as essential for the treatment of HIV.

To some of these healers, this ill treatment by health facility staff went to the extent of being excluded on health services provided to community members based on the assumption that traditional healers don't use biomedical treatment. They were easily identified by wearing traditional attires, signage outside the house and also because they are well known people in the community by people providing these community health services. One healer described being excluded from community-based HIV testing campaigns, which we intended to offer tests to all members of the community.

> *"I see these people walking around here with maroon t-shirts and I see them going into other households but I didn't know what they were doing until you told me. No one ever walked in here and offered to test me for HIV or anything, maybe they don't come in because I am a traditional healer"* (*Male diviner,SA19).*

Some healers reported having experienced bad attitudes when they took their clients and family members to the local health facilities. This perceived and experienced stigma is a threat to care which can be an obstacle both to healers' own health care and to their likelihood of referring their clients for biomedical treatment. In addition, the perceived and experienced discrimination by healers from the biomedical health care staff is a threat to care which can be an obstacle to

active client referral. Some healers explained that they felt like they were treated differently from people who have not been identified as traditional healers because they are healers, this happened when they took their clients and family members to the local health facilities.

4.2 Benefits and suggestions for a successful plural healing system

Collaborative measure suggested by traditional healers includes giving them a platform to be allowed to participate in (HIV testing and referral, linkage to care and treatment adherence, general support as well as using them for ART collection points) they aim to address issue of concern raised by clients them as healers. This is to facilitate service improvement and the relationship and interactions between traditional healers and clinic staff which will assist in operational measures for client flow. This is something that has not yet been implemented and healers believe that collaboration could bring more positive treatment outcomes if there were open communication lines.

> *"Things like these (collaboration in HIV management) need us to work together, so we don't separate (work in parallel). If the other to go this way and the other that way it's going to be a problem, you see now when I treat someone and I see how serious the situation is, I should be able and allowed to refer them and they should do the same if they see that we could help"(Male diviner, SA15).*

> *"We should also have our rooms there in hospitals and clinics and see people too, there are things that the doctors won't know how to treat just like they know some of the things we don't know. We have studied these herbs and we know them better" (Male diviner, SA14).*

Healers understand collaborative actions to be essential to building the relationships that will help them to be accepted when referring clients as well as creating room for discussion between them and health facility staff.

4.2.1 Promotion of HIV testing and the importance of knowing your HIV status

Participants reported that the opportunity to work together has the potential to widen coverage of people to know their HIV status. Some healers have expressed that the exposure to friends, close family members, clients and even healers themselves who are living with HIV and on ART played a role in sensitising and bringing awareness about HIV to other healers. This has helped to better understand HIV in terms of transmission, risks and treatment in general and they try to share their knowledge with their clients.

According to healers, knowing your HIV status is one of the primary assessment priorities they look out for. Based on their experiences, they believe that it is important for people to get tested.

> *"Sometimes it helps to initiate HIV based discussions with clients before they do. You can also try to read the person's mood and probe more. These people open up on most things because they have hope that we are going to help them. That is where I take the opportunity to ask about HIV and the treatment they use (Female diviner, SA14).*

> *"It is also important for us to know [clients' HIV status] so that we don't give people who are weak strong herbs, we also have to protect ourselves for anything that could go wrong" (Female diviner, SA14).*

One healer claimed that people believe that there are bad spirits after them causing illness because they haven't accepted their condition (HIV status). One healer described the kinds of conversations he had with clients in such situations, and how he helps them in the process to consider and accept an HIV test and also to accept their diagnoses, also explaining how he could improvise in a conversation to get the client tested for HIV

> *"Yes, I have a headache and I sweat at night hey, I have been bewitched' (says the client to the traditional healer) 'I thought let me run to that lady. When I get to this lady, she asks what is your story and I am like I am weak and losing energy' (says another client to the healer) (softly) 'what is wrong? Let me check what it could be but first of all (pause) we also do HIV testing here.' We tell them and offer, you see? Now there is no running away from it. We have also helped him to save his life" (Male diviner SA19).*

However, it is often difficult for them when they personally try to bring clients for HIV testing to the health facilities due to how they are received there. Healers believe that being ignored by clinic staff could result to missed opportunities for people to test, start or re-start treatment.

> *"I have been taking my clients personally to the clinic because I need to know what I'm dealing with and its best if they know their HIV status. It is always better when you are with someone [for the client] but the problem is that at that clinic they don't take me serious" (Male diviner, SA19).*

Traditional healers explained that when people know their HIV status and disclose to them, it shapes the treatment options to be provided to the client, allowing them to consider the condition and medication used when planning treatment for them. One of the healers reported that knowing a client's HIV status is important because it allows them to determine whether long-term sicknesses are related to dark spirits or whether the cause of their ills are HIV related or both factors to be considered but guided by what divination reveals.

4.2.2 Linkage to care and treatment adherence support

Healers acknowledged poor understanding of the epidemiology of HIV and that being one of the reasons they do not try to treat those living with HIV themselves in the absence of ART. They rather claim that they refer clients to the clinics where they feel it necessary to asses for ART legibility and initiation. *"HIV is still a mystery to many of us"* said one healer based on his understanding of the complexity of HIV, stating that curing HIV is something beyond their expertise.

> *"I still don't understand how their ARVs work in preventing a child from getting HIV in a pregnant woman. You see this child is in your body and one blood with you and how does a child gets saved if this is in your blood?" (Male herbalist, SA15).*

It appears that healers make these judgements based on observations and current knowledge on HIV. They reported that they hope the same could be done when health facility staff come across issues they feel are beyond their scope of practice. Despite the expression of poor or no relationships between traditional healers and their local biomedical health providers, some healers reported that they choose to continue making direct contact with the clinics.

Most healers described how they continue to assist their clients in various ways such as active referral to hospitals and clinics for HIV treatment re-starting (for those who defaulted) or treatment continuation, checking up on treatment progress and challenges and follow-ups on disease progression such as viral suppression for HIV. Most healers expressed that treatment adherence is important in any form of treatment, whether it is traditional medicine or biomedical treatment, and treatment interruption is one of the challenges they also come across in their own healing practices when people starts feeling better.

> *"Knowing your status is important and I see them working (referring to ARVs) because when a person uses his treatment properly it [HIV] gets drunk, this virus yeah it doesn't*

finish it completely. I have seen people recovering and getting back their body size. You can never tell if they are HIV positive like before and I always tell people not to stop (treatment) maybe one day there will be a cure" (Male diviner, SA19).

Different healers expressed mixed experiences with the biomedical care system some good and some bad but they stated that the same could be said of their services too. Some traditional healers claimed that the biomedical sector has more trust from people when compared to traditional healing. But, they continued, some people have bad experiences and that can also cause loss of confidence in the system.

One participant expressed that mistakes do happen when working with people but all parties, both people and health providers, have a responsibility to make sure you address questions and explain things to people. He described how he tries to help clients to ensure that they are getting the right medical treatments:

"So I said to him with regards to medication, focus more on treatment (ARVs). He collected, collected, collected his treatment and then now before December they changed his pills and gave him wrong pills. He used them and he came here to me and I saw him with swollen feet. I asked which treatment are you using '+Makhi+? (a person's name)' I said 'please show me.' And I said 'your first pill container wasn't like this. Do you see that these pills are not the same like those ones? Take them back.' They took them and said they are the wrong ones. Now he mustn't take them and they gave him pills to clean the damage made by those" (Male diviner, SA19).

There was a general consensus among healers we spoke to that their role is underestimated by the nursing staff at the clinics and the they believe that they make a difference in people's live and treat some conditions successfully. They also expressed that their role goes beyond what is generally assumed by people limiting the practice only to witchcraft related issues claiming that those people little about traditional healing. Even though there are no records on the

number of people referred by healers for testing and treatment formally, they could have a good impact due to the numbers of clients they could refer including their friends and families.

4.3.3 Healer's perspectives on barriers to care and adherence

Traditional healers described a number of barriers that their clients reported experiencing in accessing care in the biomedical health system. They emphasised that people complain about long queues, leading them to miss out on work, sometimes resulting in job losses. They also spoke of clients' fears of being seen at the clinic by friends and neighbours. They described how the layout of services at health facilities has a potential to make an indirect disclosure of one's HIV status for those who are not yet ready to do so.

> *"Eh you will mock me because of my AIDS that I have, that is why I was saying at the clinics a person shouldn't be separated and divide those with HIV on this side and those for what [other illnesses] that side, they must put things on the same side and call people on the same window. That way really that thing is not right" (Female diviner, SA14).*

By contrast, traditional healers provide care in their own homes, thus providing clients with privacy. If they could be included in formal HIV care, they see an opportunity for their home-based practices to be an effective location for treatment distribution or collection points, as they think people feel more comfortable accessing treatment in their homes due to the lack of risk of exposure. However, they also acknowledged that there are people, mainly professionals, who do not want to be known or want to be seen accessing care from the traditional healers just like those who don't want to be seen at the clinics

> *"I won't go there to that place man (referring to the clinic) and now they run there and come here, and when they come here they don't come in time that I had ask them to come they wait until it's dark because they don't want people to see them. They come to me and when they get here I look at them and I see that there is something wrong (referring to clinical signs of serious illness) and I ask them to come during the day so that I can assess them properly" (Female diviner, SA19).*

Traditional healers also operate outside normal office operating hours and on weekends, meaning that they are able to reach to more people. These extended hours could also be of benefit in efforts to expand treatment distribution strategies.

> *"There are professional and people with money who don't want to be known that they come to us, these are the same people who don't want to be seen at the clinics and they will come when its' very late and dark because they have cars and we don't complain we help them" (Male herbalist S14).*

Further, healers claim that they recounted clients' reported experiences of ill treatment by health providers.

> *"A sick person is very sensitive and sometimes they don't want ask because nurses shout at them in front of people, this happened when I took my client back at the clinic who was given the wrong ARVs, I had to stand up for her because he was being shouted at because it was not his appointment date" (Male diviner S19).*

The number of example highlighted by healers as barriers to care supports the benefits of having healers working in collaboration with the clinics as well as the benefits of healers being part of treating PLHIV. They have noted experiences with mistakes that happened on medication given to clients, identified people who have interrupted treatment, encouraged and actively assisted people to link back to care as well as the continued promotion to test and know one's HIV status. These are few example on things in which they could assist with, expanding and decentralizing HIV care for a wider coverage.

CHAPTER 5: DISCUSSION AND CONCLUSION

5.1 Discussion

The study explored the role played by traditional healers in HIV care and other health conditions. Understanding traditional healers' perspectives on how their healing practices and services can benefit PLHIV is important in order to understand the complexity of their interventions to deal with other common illnesses and HIV. The responses from interviews held with traditional healers identified a number of ways in which healers supported and offered care to PLHIV. These included a description in the scope of practice and the distinct role between the diviner and herbalists.

Unlike past research, which has often focused on more rural areas where traditional healing is commonly used because of various reasons including difficulties in accessing biomedical care, this study focused specifically on understanding the impacts and benefits of plural healing in peri-urban communities in the Western Cape, which are relatively better-resourced than most rural parts of South Africa. Further, these communities have relatively easy access to biomedical health care facilities, with a variety of health facilities that are accessible within walking distance of most people in our study communities. Nonetheless, many people in our study communities continue to access care from traditional healers.

The results offer insights into how healers describe the different roles and responsibilities they undertake and what it means to them as a traditional healer to provide care holistically in the context of HIV. Healers highlighted that there is a lot of improvisation linked to their work as each client had to be treated and accommodated differently. Addressing medical issues requires paying attention to contextual and sociocultural factors in both getting to the bottom of the illness cause and deciding on treatment in biomedicine (WHO, 2014). These are the same principles and strategies used by traditional healers when managing their clients. Some of the

strategies used by healers includes reaching out to family members on issues that requires broader social and familial support, promoting HIV testing, encouraging active linkage to care by personally taking their client to other health providers for a second opinion, and supporting treatment initiation or restarting. Prevention is one of the most important elements in the fight against HIV and healers have a role to play from as simple as offering or providing condoms to their clients the same way it is done at the clinics.

Traditional healers explained that they take part in assisting clients in making choices on how to balance or choose between taking ART, traditional herbs or both by using their discretion and the condition of the client. However, healers acknowledged that their recommendations are limited the findings of the divination outcomes and physical state of a person and does not extend to bodily examinations and other tests compared to the clinics and hospitals. These findings complement those of Moshabela and colleagues (2016), who found that traditional healers played a positive role in HIV management by promoting HIV testing and early treatment initiation and encouraging patients to remain in care. Furthermore, our results highlight changes and progress made by traditional healers to try and understand HIV and treatment. This is a shift from findings of some other studies on the issue of traditional healers, which have identified healers as the cause of delayed access to HIV care and treatment.

The findings demonstrates a shift in the mind-set of healers, suggesting greater openness to taking progressive steps towards collaboration in the fight against HIV. This movement requires genuine partnership and active efforts to break through the existing boundaries between these two sectors, which are influenced by long histories of division and discord. For further progress to take place, there is a need to understand that medical pluralism extends beyond the socio-cultural context, not limited to a particular race, place or certain cultural and traditional practices. Tradition, culture, time and space as well as socio-economic elements all contribute

to shaping individuals' responses to why, when and where, as well as from whom, they seek care (Moshabela et al., 2017).

The empirical complexity of people's conceptions of health, their health-seeking behaviour and their general approach when dealing with life challenges requires consideration in order to build a working relationship between different health sectors. Currently, efforts to engage and include healers are one sided and focus primarily on training healers in the biomedical system, rather than learning from healers' existing expertise and recognising the importance of the social support they offer. This research identifies some milestones to be addressed in order for the biomedical and traditional healers to work together. This includes the formal recognition of the traditional healing profession, better understanding of traditional healing practices and addressing negative judgments towards healers imposed by those who do not understand the practice.

In the early to mid 2000's when the HIV epidemic was at its peak in terms of mortality, biomedical practitioners played a role in providing care similarly to other illnesses to yet what was still to be better understood. On the other hand, traditional healers also gradually came into play, striving for recognition and reclaiming their existence and legitimacy in HIV care (Levine, 2012). After many years of democracy, there are still differences in what is considered to be legitimate and acceptable to be used by the public while some practices are still undermined. Some of the factors that perpetuate the differences in what is generally considered as acceptable are misconceptions on traditional healing practices and its association with witchcraft. These misconceptions about traditional healers continue to act as a barrier to collaboration and yet there are no actions made in using their voice in discussions in the public health sector in order to redress some of these misconceptions (Bantjes et al., 2018).

Traditional healers provide health services that could be expanded and enhanced with greater government support (Devenish, 2008). Nguyen (2010) argues that global bio-political initiatives are often less effective when translated locally and context must be considered more carefully when interventions are designed for better adaptation. I would go beyond this argument to specifically suggest that interventions need to engage with local healing systems to account for local understandings of illness and plural practices of healing.

In order to ensure that interventions to support the HIV care cascade work well for all, we need to find inclusive and engaging strategies that will improve health care by using local resources such as traditional healers. Understanding and accepting people's preferences will open doors to negotiate care based on people's own preferences and create a working plural healing system. This could make it easier for people to talk openly about their care preferences with nurses and doctors, as well as society in general, without fear of judgement or discrimination. This could mean that people would have a variety of options for holistic and personalised care meeting individual needs and used without fear of prejudice.

5.2 Study limitations

There were some limitations in conducting this research project that need to be acknowledged. The first limitation relates to the logistics of data collection and data processing. While I sought to do as many interviews with healers as possible, some of the data were collected and transcribed by different researchers from our study team, who might have had different perspectives on traditional healing. A person's perspective on an issue could influence how they engage with the subject matter and how they interact with the study participants, thus shaping the data produced. Secondly, participants were recruited in public spaces, from general walks in the community and also by referral from other participants in the study. Using these approaches means that our sample is not randomly selected, and there may be biases in the kinds of healers we recruited (e.g. those who were more known or more visible in communities).

Further, there is a possibility that the pool of participants we recruited through referral by other participants had similar views on traditional healing as these are healers who closely work together as opposed to people who are not connected in any way. Also, our study was limited to healers operating and residing within our study communities. It is likely that community members also might also be accessing services from healers residing outside the study catchment area, whose views are not represented in our study. In addition our sample size is small and does not allow the findings to be generalised.

Despite these limitations, the study highlights the dynamics and challenges as well as benefits of traditional healers at a small scale in specific local township contexts.

5.3 Conclusion

The role of traditional healers in supporting HIV management is often relatively unrecognised by policy makers and biomedical health care practitioners, who often consider traditional healing practices as complicated, unexplainable, and 'unscientific.' However, the results in this study shows that there are similar steps and processes involved before and during treatment followed by traditional healers when managing their clients, such as history taking, individualised care and referral. The role played by traditional healers is not only limited to "traditional religious supernatural healing" but also goes beyond medicinal care to their clients to also encompass various forms of social support. Healers move between roles of spiritual guide, relationship advisor, treatment supporter, counsellor, and advocate to support their clients' broader psychosocial needs. In addition, healers often play a mediating role in within the plural healing system, assisting clients to navigate between different systems and structures of care.

The awareness, versatility, and openness of traditional healers' in addressing the ever changing social and health problems of those they care for could be beneficial to PLHIV as they are availing themselves in expanding HIV services such providing them with condoms to promotes

prevention, HIV testing, referral and collection points for HIV treatment. Their role thus requires greater consideration from local, provincial, and National Health Service providers. Potential avenues for more effective integration of healers into HIV care could involve more structured training in HIV counselling and testing, treatment support and referral. The possibilities of change and improvements in health systems strengthening requires inclusiveness rather than exclusiveness to reach the common goal of an HIV free generation.

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	Mark	Points possible	Expectation	Comments
Grammar and style	7	10	Is the assignment well written? Has the student edited the paper for grammar and spelling? Is it complete?	While there are still some grammatical issues, the writing is much improved from previous drafts. **External reviewer:** *I agree that there are some grammatical issues, but I also understand the background of the student and her usage of a particular register. I'd recommend that a revised version should be submitted with editing for a publication.*
Structure and flow	6	10	Does the assignment flow well? Are the paragraphs structured clearly and in a logical manner?	The overall structure of the assignment is clear. However, the paper does still jump around a bit within sections, as noted in comments in some places. **External reviewer:** *If the student had more time (I presume she is also not a full-time student/but a working professional), then she could have presented a more coherent structure.*
Background and literature	13	20	Does the research assignment cite key literature? Is there a complete bibliography that includes at least 10 outside sources? Does the student synthesis existing literature	There is evidence of substantial reading and background. However, the section is still a bit hard to follow in some places. Also, as we've discussed, it needs to draw the reader more clearly

			and locate their project within it effectively?	from the existing literature to the central questions of this study. **External reviewer:** *I agree with the comment and feedback (also in the text)*
Methods and study design	16	20	Is the research designed appropriately? Is there sufficient evidence of original research and analysis?	The research design is strong, informed through participation in the broader study. The student has conducted a good deal of primary research and has spent time working with the data to analyse it. The methods are explained clearly in this section. ***External reviewer:*** *I fully agree with the assessment here, and that the methods and study design are some of the strongest points of the work*
Findings	13	20	Are the findings clearly articulated? Are they original and demonstrated clearly through data/evidence?	Findings are interesting but could still do with a little more clarity in some areas (as commented on in previous draft) **<u>External reviewer:</u>** *I agree that the findings could have been presented a bit more coherently and with greater clarity.*
Discussion and conclusion	15	20	Does the assignment explore findings in relation to the existing field of literature? Is there evidence of critical thinking and synthesis of key concepts?	The discussion and conclusion section is quite strong. However, I do think it could benefit from more detailed recommendations for how integration could take place, acknowledging the positive roles that healers do play in offering psychosocial support and other social functions. ***External reviewer:*** *Overall a very interesting and relevant study. I agree with the mark given for the latter concluding parts of the research assignment.*

				I hope that you could work with her to develop this further into a publication.

Total: 70